No Time to Lose:

Getting More from HIV Prevention

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Executive Summary

Two decades after the first case of the acquired immunodeficiency syndrome (AIDS) was recognized in the United States, the nation does not have a comprehensive, effective, and efficient strategy for preventing the spread of the human immunodeficiency virus (HIV). The need for such a plan is becoming even more pressing as, ironically, advances in treating AIDS have helped foster a growing sense of complacency in many sectors of both the government and the general public, as well as in some populations of HIV-infected persons and those at high risk of becoming infected. Improved treatment is critically important, and efforts should be continued to extend such advances. With better treatment, more Americans are living with HIV/AIDS than ever before. However, this creates more opportunities for transmitting the virus and thus a greater need for prevention. Therefore, it is time for the nation to adopt a coordinated set of strategies to prevent the spread of HIV/AIDS. We must learn from our past successes, as well as from our failures, in prevention and we must focus prevention efforts on those individuals and communities who are increasingly affected by the epidemic.

By the end of 1999, a total of 733,374 AIDS cases and 430,411 AIDS-related deaths had been reported in the United States (CDC, 2000a). During the first decade of the epidemic, the number of new AIDS cases increased by 65–90 percent each year (CDC, 1996). In 1996, the number of new AIDS cases and deaths fell for the first time in the history of the epidemic (CDC, 1997). By 1998, the number of AIDS deaths had declined by almost two-thirds from the 1995 record high (CDC, 2000a). These declines can be attributed to advances in antiretroviral therapies (CDC, 1999a) and, in part, to a number of HIV prevention efforts carried out by federal, state, and local government agencies, nonprofit organizations, and the private sector. Most notable were prevention efforts that led to: changes in sexual behavior among men who have sex with men, reduced transmission among injection drug users, increased the safety of the nation's blood supply, and reduced perinatal transmission from infected mothers to their children. Recent data suggest that the declining trends in AIDS incidence and deaths may be stabilizing, however (CDC, 200b).

Despite the enormous successes in HIV prevention over the past decade, there are additional prevention challenges. The populations that need to be reached by prevention interventions have

changed considerably. Women, youth, and racial and ethnic minorities now account for a growing proportion of new AIDS cases, and increasing numbers of cases are emerging in rural and smaller urban areas (CDC, 2000a), whereas many prevention programs have previously focused on gay white men in major metropolitan areas. In addition, an increasing proportion of new AIDS cases are now being linked to heterosexual exposure, while a declining proportion of new cases are being attributed to men who have sex with men. Men who have sex with men still remain the largest exposure group, however (CDC, 2000a). These new at-risk populations are not being reached for prevention as effectively, or on as large a scale, as at-risk populations have been in the past, and prevention programs tailored to specific social contexts of an earlier period in the epidemic are not proving as effective during the current period.

As a result of such challenges, the Centers for Disease Control and Prevention requested that the Institute of Medicine convene a committee to review current HIV prevention efforts in the United States, to develop a visionary framework for a national HIV prevention strategy that could significantly reduce new infections, and to suggest the roles that public and private-sector agencies should have within this framework. The Committee examined the available evidence, and received much useful information and advice from federal, state, and local agencies, as well as from community organizations involved in research on HIV prevention and in implementing HIV prevention programs. The Committee's review revealed several important findings.

Above all, HIV prevention works: there is a wide range of proven strategies to reduce behaviors that increase the risk of transmitting or acquiring HIV. However, the ways in which prevention efforts are currently being implemented do not allow the nation to fully reap the benefits of these proven strategies. The Committee identified a number of problems.

First, expenditures on HIV prevention activities appear to be allocated to states in rough proportion to the distribution of persons with AIDS. While this approach may be useful for allocating funds for treatment, it is an inadequate marker of need for prevention services. Second, due to long-standing concerns about AIDS-related stigma and discrimination, prevention efforts have largely avoided interventions directed at individuals who are HIV-infected, the very persons who are in a unique position to stop the spread of HIV. Third, community organizations that try to conduct prevention programs are often hampered by inadequate dissemination of state-of-the-art prevention research and limited technical assistance for program adaptation, implementation, and evaluation. Fourth, neither the public nor the private sector has invested sufficiently in developing new biomedical tools and technologies that can help in HIV prevention. Finally, social barriers, such as poverty, racism, gender inequality, and the stigma attached to HIV and AIDS, continue to seriously impede HIV prevention efforts.[1]

The Committee also found that there is a definite lack of federal leadership with regard to HIV prevention. While the Committee does not focus in this report on the role of federal leadership, we are well aware that there have been longstanding problems related to such issues as agency organizational and structural factors and the lack of intra- and interagency coordination. Many

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[1]Although the Committee's charge was limited to examining and providing a visionary framework for HIV prevention in the United States, significant attention must also be directed to improving HIV prevention efforts at the global level and to ameliorating the devastating impact that HIV/AIDS has had in developing nations.

different agencies now share responsibility for federal HIV prevention activities (see Appendix C). These agencies are funded through different sources, serve different constituents, have programmatic responsibilities other than HIV, and report to different congressional oversight and appropriations committees. Sometimes, these agencies compete for resources and public attention. While federal agencies and officials have tried several different leadership models, none has been very effective in bringing about the type of overarching guidance needed to coordinate federal prevention agencies and activities, as well as to bring together the wide variety of DHHS, non-DHHS, and outside agencies that are involved in HIV prevention efforts. Reclaiming federal leadership of the nation's HIV prevention strategy requires better coordination of efforts currently too dispersed. The implementation of even the best prevention strategy will not be fully effective under conditions of poor leadership and inadequate political commitment. The Committee believes that, for HIV prevention efforts to have maximum impact, there must be a strong, clear leadership structure in the Department of Health and Human Services.

From these findings, the Committee recommends a new strategy for preventing HIV infections. As a starting point, the nation should adopt an explicit prevention goal: **To avert as many new HIV infections as possible with the resources available for HIV prevention**. While this may seem an obvious goal, the Committee found that many current HIV prevention efforts are inconsistent with this principle. To reach this goal, a new vision is needed that will improve the way the epidemic is monitored, change how prevention resources are allocated and how activities are prioritized and conducted, foster interactions between the public and private sectors to promote new prevention tools and technologies, and reduce or eliminate social barriers to HIV prevention.

This strategic vision comprises six elements:

- Develop an accurate surveillance system, focused on new HIV infections, that can better predict where the epidemic is headed.
- Allocate prevention resources to prevent as many new HIV infections as possible, guided by principles of cost-effectiveness rather than simply by the number of AIDS cases.
- Direct prevention services to HIV-infected persons, who often have been excluded from prevention activities, and integrating prevention activities into the clinical setting in order to reach people at high risk of becoming infected.
- Translate findings from prevention research into action at the community level.
- Invest in the development of new tools and technologies to expand HIV prevention efforts.
- Strive to overcome social barriers and to remove policy barriers that impede HIV prevention.

DEVELOPING AN ACCURATE SURVEILLANCE SYSTEM FOCUSED ON NEW HIV INFECTIONS

To best plan and evaluate prevention activities and allocate resources for HIV prevention, a national surveillance system is needed that identifies new HIV infections (HIV incidence). The current epidemiological surveillance system – which is based primarily on AIDS case reporting and, more recently, on HIV case reporting in selected states – does not provide a complete or accurate picture of HIV incidence. By focusing mainly on AIDS cases, where diagnosis lags approximately 10 years after HIV infection without treatment and even longer than 10 years with potent new antiretroviral therapies, today's surveillance system looks at the past rather than to the future. The system tracks where the epidemic has been rather than where it is going. This lag is particularly problematic in light of the reality that the epidemic has shifted into new population groups. Thus, to more effectively direct prevention interventions to communities at risk, the Committee recommends that:

The Centers for Disease Control and Prevention create a surveillance system that can provide national population-based estimates of HIV incidence. The recommended surveillance system would estimate new HIV infections using blinded serosurveys of well-characterized sentinel populations (e.g., drug users in treatment, and people attending sexually transmitted disease clinics and tuberculosis clinics, and clinics serving women of reproductive age), surveys that characterize the populations served by those sites, and advanced testing technologies that are able to identify recent HIV infections.

ALLOCATING RESOURCES TO PREVENT AS MANY NEW HIV INFECTIONS AS POSSIBLE

The current distribution of federal funds for HIV prevention can best be described as an amalgam of administrative and legislative decisions that have been shaped in response to available data, Congressional mandates and earmarks, constituency pressures, personal values, and the professional judgment of program managers. The allocation strategy that results from these cumulative decisions can best be described as "proportionality." As a prevention strategy, proportionality has one important advantage, in that it begins with an objective criterion of need – that is, observed AIDS cases. However, proportionality has serious limitations, including the fact that it is an inadequate marker of need for the purposes of prevention. Proportionality rewards the reporting of AIDS cases rather than the prevention of new infections. Also, current funding decisions too often ignore the cost-effectiveness of interventions, and agencies that fund prevention research activities often fall short of requiring (and funding) assessments of the cost-effectiveness of programs or interventions tested. The Committee believes that in order to avert as many new infections as possible, better decisions about the overall investment of prevention resources must be made. To this end, the Committee recommends a strategy of allocating funds based on HIV incidence and the use of cost-effective interventions. Directing prevention efforts to populations at high risk of infection, and using interventions of proven efficacy and cost-effectiveness, could prevent an estimated 20 percent to 30 percent more infections than does the

current allocation of HIV prevention funds (see Chapter 3). Thus, the Committee recommends that:

Prevention resources should be allocated to prevent as many new infections as possible. Such an allocation must take into account the cost and effectiveness of programs, in addition to estimates of HIV incidence. Evaluation should be a major component of resource allocation decisionmaking. With better evaluation data reflecting the cost, efficacy, and reach of programs, resources could be more profitably invested in interventions that work. Interventions that do not work, or that are very expensive relative to the number of infections prevented, could be abandoned.

USING THE CLINICAL SETTING FOR PREVENTION

Every new HIV infection begins with someone who is already infected – yet current prevention programs do not emphasize directing prevention efforts to individuals who are HIV-infected and who may still engage in risky behavior. Ideally, prevention interventions should be available for all HIV-infected persons. According to recent data, the majority of HIV-infected persons who know their status are in the treatment system (Bozette, et al., 1998) and may receive at least some information about prevention. However, it is estimated that up to one-third of infected persons do not know their HIV status (CDC, 1999b). Efforts should be made to increase the number of infected individuals who are aware of their status. In addition, individuals at high risk for HIV infection often come in contact with the health care system for services at a variety of different entry points, and each of these clinical settings provides valuable opportunities for delivering HIV prevention services. Thus, the Committee recommends that:

Prevention services for HIV-infected persons should be a standard of care in all clinical settings (e.g., primary care centers, sexually transmitted diseases clinics, drug treatment facilities, and mental health centers). Health care providers should have adequate training, time, and resources to conduct effective HIV prevention counseling. Enabling this activity may require adjustments in health care provider time allocations and/or specific financial incentives from public and private sources of health coverage.

TRANSLATING RESEARCH INTO ACTION

Limited information is available on the performance and cost-effectiveness of prevention programs when implemented in community settings under nonexperimental conditions. This type of information is needed to ensure that programs of proven efficacy achieve maximum possible effectiveness and cost-effectiveness once integrated into practice, to insure that sound evaluation data are available at the community level, and to ensure that effective prevention programs are translated and disseminated into communities. As a result, the Committee recommends that:

Key Department of Health and Human Services agencies that fund HIV prevention research and interventions should invest in strengthening local-level capacity to develop, evaluate, implement, and support effective programs in the community. The Committee further recommends that these agencies invest in research on how best to adapt effective programs for use in community-level interventions and research on what constitutes effective technical assistance for optimal research-to-community transfer of prevention programs; these agencies should also be responsible for the widespread dissemination of the results of this research. Such efforts will require the participation and collaboration of the funding agencies, researchers, service providers, and communities.

INVESTING IN THE DEVELOPMENT OF NEW TOOLS AND TECHNOLOGIES FOR HIV PREVENTION

Given the success that technologies have had in preventing HIV – such as antibody tests used to screen the blood supply, and drugs to prevent perinatal transmission of HIV – investment in new tools and technologies is clearly warranted. Research and product advances in the areas of HIV vaccines, antiretroviral and antimicrobial therapy, microbicides, and barrier methods (female condoms) can significantly increase the effectiveness of HIV prevention efforts. However, there are significant barriers to development, approval, and distribution of technological innovations. Such barriers include insufficient funding to maintain research on product development and testing, as well as lack of interest in the development of specific products. The timely development of new products will require the promotion of public and private sector collaborations and the development of incentives to increase involvement by private sector industries and philanthropic sources. Thus, the Committee recommends that:

Federal agencies should continue to invest in the development of products and technologies linked to HIV prevention. In particular, the National Institutes of Health should place high priority on the development of anti-HIV microbicides and vaccines, and this prioritization should be accompanied by increases in funding. Similarly, the Food and Drug Administration should accelerate its efforts to approve prevention technologies that show promise in clinical trials (e.g., new antiretroviral therapies, new microbicidal and vaccine candidates) or are already being successfully utilized elsewhere in the world (e.g., rapid testing assays other than the Single Use Diagnostic System [SUDS]). For all new prevention tools, investigations of cost-effectiveness and user acceptability should be included as part of the research agenda. Federal agencies should also seek to develop stronger research collaborations with private industry, and they should offer incentives to encourage private industry investment.

STRIVING TO OVERCOME SOCIAL BARRIERS

Social, economic, and cultural forces not only shape the progression and course of the AIDS

epidemic but also influence this nation's response to the epidemic. Societal attitudes surrounding sexual activity and drug use have fostered policies that have created barriers to the implementation of proven HIV prevention interventions and the efficient use of prevention resources. The consequence is missed opportunities to prevent new HIV infections, resulting in lost lives and wasted expenditures. National leadership is urgently needed to provide a coordinated strategy for effectively overcoming these social barriers in order to capitalize on the unrealized opportunities in HIV prevention. Thus, the Committee recommends:

- **Increasing drug abuse treatment funding to levels that are sufficient to provide drug treatment to all those requesting it;**
- **Removing legal and policy barriers that limit access to sterile drug injection equipment;**
- **Eliminating congressional, federal, state, and local requirements that public funds be used for abstinence-only education, and that states and local school districts implement and continue to support age-appropriate comprehensive sex education and condom availability programs in schools; and**
- **Removing policy barriers that hinder the implementation of effective prevention efforts in correctional settings.**

The Committee believes the nation can and should do more to prevent HIV infection – and we have no time to lose. Doing better will require a new way of thinking about cost-effectiveness as a guiding principle for HIV prevention. It will require new leadership, accountability, and coordination. It will require directing interventions to those who are HIV-infected and to those – the women, youth, and racial and ethnic minorities – who are increasingly affected by the epidemic. It will require more effective translation of interventions that prevent HIV in research settings into activities that are effective in communities. And it will require removing obstacles that impede the implementation of those interventions that we now know to be effective.

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